2005

Factors associated with late presentation for HIV care among patients in Hinche, on Haiti's Central Plateau

Coeurlida Louis
Yale University

Factors Associated with Late Presentation for HIV Care Among Patients in Hinche, on Haiti's Central Plateau

Cecurilda Louis

YALE UNIVERSITY

2005

Factors Associated with Late Presentation for HIV Care Among Patients in Hinche, on Haiti's Central Plateau

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

By

Coeurlida Louis

2005

ABSTRACT

FACTORS ASSOCIATED WITH LATE PRESENTATION FOR HIV CARE

AMONG PATIENTS IN HINCHE, CENTRAL HAITI

Coeurlida Louis[a], Louise Ivers[b], Ken Freedberg[c], Mary C. Smith Fawzi[bd], Arachu Castro[bd], Frank Bia[a]. [a]Department of Medicine and Laboratory Medicine Yale University School of Medicine, New Haven CT; [b]Division of Social Medicine and Health Inequalities, Department of Internal Medicine, Brigham and Women's Hospital, Boston MA and Partners In Health, Boston MA; [c]Massachusetts General Hospital, Boston, MA; [d]Program in Infectious Disease and Social Change, Department of Social Medicine, Harvard Medical School.

Haiti has the highest HIV prevalence in the Caribbean and Latin America and is the poorest country in the Western Hemisphere. Many patients with HIV infection present for care late in the course of their disease, a factor which is associated with poor prognosis. Our objective was to identify factors associated with late presentation for HIV care among patients in central Haiti.

Thirty-one HIV-seropositive adults, or approximately 10% of the HIV-infected population followed at a central Haiti hospital, participated in this research study. A two-part research tool that included a structured questionnaire and an ethnographic life history interview was used to collect quantitative as well as qualitative data about demographic factors related to late presentation for HIV care.

Sixty-five percent of the patients in this study presented late for HIV care e.i-with CD4 cell count below 350 cells/mm^3. Factors associated with late presentation for HIV care included lower socioeconomic status ($p<0.02$), older age ($p<0.05$), greater distance from the medical clinic ($p<0.005$), and lack of prior access to effective medical care ($p<0.04$). In addition, male sex, patient belief that symptoms are not caused by a medical condition and prior negative experience with local hospitals also influenced timing of patient presentation. Harsh poverty was a striking theme among all patients interviewed, and was intricately associated with many of these reported factors.

Delays in presentation for HIV care in rural Haiti are linked to demographic, socioeconomic and structural factors, many of which are rooted in poverty. These data suggest that a multifaceted approach is needed to overcome barriers to early presentation for care. This approach which might include poverty alleviation strategies, provision of effective, reliable and free medical care, patient outreach through community health workers and collaboration with traditional healers, could improve HIV case detection and reduce morbidity and premature mortality from AIDS.

ACKNOWLEDGEMENTS

This work is dedicated to my Mom, Marie-Thérèse, Dad, Dartigue, and to my husband, Matthew.

I would first like to thank the patients for participating in this study and for inspiring me.

I would also like to thank:

Paul Louis for insight and help with the translations; Ermaz Louis for introducing me to patients and making the initial patient home visits with me; Thanks to Pierre-Paul, Loune Viaud, Fernet Leandre, the entire Partners In Health / Zanmi Lasante staff in Haiti and in Boston for their help and support, and to Joia Mukherjee for allowing me to come on board. I would especially like to thank Mary C. Smith Fawzi for her thorough comments and valuable insights and direction; Louise Ivers and mentor Ken Freedberg for their ongoing inspiring work and brilliant research questions; Arachu Castro for her guidance on the qualitative aspects of the work, and my advisor Frank J. Bia for his guidance. I am indebted to Dr. Valentine Njike from the Yale Prevention Research Center for his kind and patient help with the quantitative statistics analysis. I thank Krystn Wagner M.D. Ph.D. for her review of the thesis, and the Yale Office of Student Research for its support of the research activity.

TABLE OF CONTENTS

I. INTRODUCTION

a. World AIDS statistics

Since its surfacing into the public consciousness in the early 1980's the human immunodeficiency virus (HIV-1) has become the substrate for a devastating worldwide epidemic, causing its deadliest damage in the world's poorest nations. Currently there are between 35.9 to 44.3 million people living with HIV worldwide and the vast majority of those infected, over 95%, are living in countries and areas crippled by poverty, without access to the lifesaving antiretroviral (ARV) medications or HIV care [1,2]. Acquired immunodeficiency syndrome (AIDS) caused by the HIV viruses is a leading cause of death and suffering worldwide. The World Health Organization (WHO) estimates that 3.1 million people succumbed to the disease last year. Not surprisingly, given the connection between poverty and HIV, most of the dead, 2.3 million, were in the poverty stricken countries of sub-Saharan Africa. Moreover, of the estimated 39.4 million HIV infected individuals in the world, nearly two thirds, or 25.4 million, live in sub-Saharan Africa [1].

While the HIV epidemic is taking its greatest toll in the world's poor and developing countries, sadly, it is also in those places that the highest rates of new HIV infections are being found. 4.9 million new HIV infections surfaced in 2004 alone, most of them, 3.1 million, were from the sub-Sahara region [1]. Needless to say, Africa is taking the brunt of the AIDS epidemic, but this paper will focus on Haiti, a country which is so ravaged by AIDS, it might as well be considered a part of sub-Saharan Africa.

In developed countries where financial and human resources are both available and allocated to fight the HIV epidemic, effective education campaigns, prevention

efforts and treatment focuses have successfully curbed the growth rate of HIV infections and reduced deaths from AIDS. As an example, North America with a total of one million HIV infected individuals, has a significantly lower HIV prevalence rate of 0.6% compared to a 5.7 % prevalence rate in neighboring Haiti [1]. In North America where the epidemic is relatively well controlled, there were 44,000 new cases of HIV last year, compared to 53,000 new cases arising from the far less populous Haiti and the Caribbean.

b. Haiti and the Caribbean

Not all the Caribbean islands are equally affected by the HIV epidemic, in fact the HIV prevalence cited for that region can be attributed mostly to HIV in Haiti. The HIV epidemic began in Haiti in the late 1970's and has spread throughout the country since. While the total Caribbean HIV prevalence is estimated to be 2.3%, the prevalence rate in Haiti, 5.7%, is more than double that value. Besides having the highest prevalence in the Caribbean and Latin America, Haiti faces the worst AIDS epidemic worldwide, outside of Africa [3,4].

About 10,700 square miles in area (roughly three times the size of Puerto-Rico), the western one-third of the Caribbean island of Hispaniola with a population of about 8 million people, Haiti claims more than 300,000 of the 440,000 total HIV infections of the Caribbean islands [3,4] (See figure 1 for map of Haiti). It is estimated that 85 % of people living with HIV in the Caribbean are in Haiti and the Dominican Republic alone [5]. Although HIV has been diagnosed in every country in the Caribbean, none of these countries comes close to matching the number of infections found in Haiti. The Dominican Republic, the eastern part of the shared island of Hispaniola comes the closest

with 88,000 total infected individuals [3]. Based on HIV surveillance among pregnant women, the HIV prevalence in Haiti varies widely between 2.5 % and 11.9 % and in the northwest region of the country, the rate is estimated as high as 13% [4]. Higher national prevalence rates can only be found in sub-Saharan Africa [1]. This makes Haiti the second most heavily affected area in the world after sub-Saharan Africa. In all, AIDS is having a devastating effect on Haiti's population; it is the number one killer of adults aged 15 – 44 years. 24,000 to 30,000 people die of HIV/AIDS on the island each year and 200,000 children have been made orphans by the epidemic [4].

Heterosexual intercourse, as opposed to homosexual intercourse or drug injection, is the overwhelming mode of HIV transmission in Haiti, accounting for over two-thirds of the AIDS cases there [3]. This means that women, their children and the young sexually active population are very frequently affected by the epidemic. Indeed women make up nearly 50% of those infected in Haiti. Economic difficulties that force women into situations of increased HIV risk play a major role in the dissemination of disease among that group in Haiti. About 60% of Haiti's total population is less than 24 years old [3]; this fact, combined with very low condom use among the youth in Haiti make for a very grim prognosis for Haiti's primarily heterosexually driven AIDS epidemic. In just five years, by 2010, the already short 50 year life expectancy of Haitians is projected to shorten by another 10 years, because of the AIDS epidemic [1].

With its large HIV infection burden, Haiti, like many of the affected third world nations of Africa has the national setting of absolute poverty, with low health and developmental indices that provides the conditions for propagation and worsening of the HIV epidemic. To begin to understand its singly outstanding HIV toll in the Americas,

one only has to understand the country's repetitive claim to fame as the poorest nation in the Western Hemisphere.

c. Central Haiti and Hinche, the study site.

In the mid 1980's Dr. Paul Farmer began providing medical services to the residents of Haiti's central plateau, and in 1987, he and other individuals founded the non-profit organization Partners In Health (PIH) which has for motto: improving the health of people living in poor communities. Today PIH has expanded to five sites in Haiti's central plateau, providing medical care in collaboration with the Haitian Ministry of Health. The health services provided free of charge to patients, include comprehensive general medical care and treatment of HIV. One of the PIH sites at Cange, which started out as a small clinic, has evolved over the years into a 104 bed tertiary care center complete with two operating rooms, adult and pediatric inpatient wards, a tuberculosis treatment facility, a well stocked pharmacy and a blood bank (See Figure 2 for map of central Haiti and the PIH clinical sites).

Having successfully worked in Haiti for over 20 years in the fight against tuberculosis (TB) and HIV, Dr. Farmer and the workers of Zanmi Lasante (ZL), Creole for Partners In Health, were recognized for their effective battles against disease Haiti. In 2002 the organization was awarded a five year $13.5 million grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria [6]. The grant was awarded to help the organization's efforts to reach and treat Haitians living with HIV and AIDS, and will also help Haiti attain its part of World Health Organization's (WHO) global '3 by 5' initiative.

WHO's '3 by 5'initiative is a global campaign against the AIDS epidemic with the goal of having 3 million HIV patients on ARV treatment by the end of 2005 [6].

It is estimated that about 40,000 patients actually need ARV treatment in Haiti now. In the central plateau, PIH's catchment area, 25,000 are believed to be HIV-seropositive and 10% or 2,500 may now need antiretroviral therapy [6]. The Global Fund's target is to reach 50% of Haiti's total treatment need or 20,000 patients by the end of 2005 [6]. In 2003 the total antiretroviral disbursements for HIV patients in Haiti went to about 1370 patients [6] so it will be no small feat to reach tens of thousands more in just two years. HIV programs have been available to patients in Haiti's central plateau through Partners In Health since 1986. PIH has been providing antiretroviral therapy successfully to patients in the plateau for years, but as HIV medications become available in some settings for the first time, efforts to scale up existing local health systems and expand PIH's reach become crucial in order to meet the Global Fund treatment goal for Haiti.

Hinche, the capital city of Haiti's central plateau, represents one of the PIH expansion sites for the Global Fund project, and is the site of this study. Historically, the only health services available to the population of Hinche came from a state operated hospital that provided medical services with minimal resources. The Hospital St. Thérèse staff saw about ten patients a day until PIH's recent partnership with the hospital [7] (See figure 3, St. Therese Hospital). The city of Hinche reflects the country's national HIV and economic statistics. Its population of 53,000 is made up mainly of farmers and laborers, and most are living on less than one U.S. dollar a day [8], as is true for the rest of Haiti. Almost half the population in that region cannot read or write with the grim

literacy rate of only 52 % [8]. It is in this setting that PIH expanded this past year, and set out to seek and treat those with HIV and AIDS.

d. Background of late presentation for care

In trying to meet the treatment goal for the central plateau and Hinche, one of the most daunting tasks for PIH is 'case detection' or "identifying HIV positive people to enroll" [9]. In Haiti, much like in the rest of the developing world, patients tend to present for HIV testing diagnosis and care, late in their disease process, when their CD4 counts are already below 350 cells/mm^3 or they are in need of antiretroviral therapy [9]. According to preliminary data collected by Ivers, over 80% of the HIV patients in one part of Haiti's central plateau who presented for their first clinic visit, had CD4 counts below 350 cells/mm3 [9].

Late presentation for care of HIV infection is associated with poorer long-term prognosis for patients [10,11]. It cheats patients with HIV infection of the maximal benefits of antiretroviral therapy, screenings for sexually transmitted diseases, and tuberculosis as well as educational and prophylactic interventions that are more effective when implemented earlier in the disease process [10]. Late presentation with HIV can mean worsened morbidity and premature mortality. It need not continue in the face of currently available antiretroviral medications, available free of charge to the patient, in Haiti's central plateau. Identifying and understanding factors that bring people to the hospital late in their disease process could translate into the development of better outreach measures, thus allowing patients with HIV infection, who sorely need earlier treatment, to be better engaged by the health care system.

II. STUDY OBJECTIVES

The study's aim is to identify factors associated with late presentation for HIV care among patients in Hinche, central Haiti. The hope is that an understanding of these factors could lead to more effective HIV case detection and reduce suffering and premature mortality from AIDS. Some patient groups tend to present later than others for HIV testing diagnosis and care; we hypothesized that certain factors such as male sex, relatively low socioeconomic status and low education level, as well as greater distance from the clinic, would be associated with later presentation for HIV care.

III. METHODS

a. Study setting

This study was carried out in the city of Hinche, capital of Haiti's central plateau region where this past April 2004, Partners In Health (PIH) entered into a collaborative partnership with the Haitian Ministry of Health to treat the HIV-positive population of the region at the Hospital St. Thérèse. PIH's Haitian staff and doctors oversee and run the HIV and infectious disease ward of the Hospital, the Pavillion Monseigneur DeCoste (See figure 3). Before the arrival of PIH, the hospital staff saw less than a dozen patients a day [7] gradually, as free care and medications became available through PIH, the clinic staff saw an increasing number of patients daily. Since PIH's arrival, more than 200 HIV patients have been identified through screening, and more than 100 of these patients are now on ARV therapy [12]. This study was carried out to investigate the factors associated with the timing of patient presentation to the clinic for HIV care, and, through this

process, gain an understanding of why so many patients in rural Haiti present late for HIV care.

b. Patient population and study design

The patient population accessing the St. Thérèse clinic comes from the city of Hinche and the surrounding rural towns. It is mostly made up of local peasant farmers and unskilled laborers. Inclusion criteria for the study consisted of adults ages 18 to 70 that presented to the PIH HIV/TB Pavillion of the St. Thérèse Hospital for care, and were diagnosed with HIV. Selection for participation involved recruiting an approximately equal number of men and women to ensure analysis of potential gender differences in late presentation for HIV care.

The research approach was a combination of both quantitative and qualitative methods [13,14]. In November of 2004, about six months after the establishment of PIH at the St. Thérèse Hospital, incoming patients were invited to participate in the research study. Recruitment consisted of verbally asking patients who accessed the clinic and who were HIV positive, to participate in the study. Thus, patients were selected from the target population of HIV-positive patients accessing the clinic.

The first thirty-one HIV-positive patients approached accepted to participate in the study. Since the clinic followed about 300 HIV-positive patients at the time of the study, approximately 10% of the total HIV-positive population being cared for by the hospital were included in the study. Including at least 10% of the St. Thérèse HIV-positive patients might help ensure that information gathered from the interviews could be potentially applicable to the wider HIV-infected population being followed by the

hospital. In qualitative research, a relatively small sample size is considered appropriate since the focus of that research involves more detailed, open-ended, and in-depth data collection and looks for variability more than for statistical representation [14].

c. Data collection

Each patient provided written informed consent in accordance with the requirements of the Institutional Review Board of both the Brigham and Woman's Hospital and the Yale School of Medicine. Factors associated with the timing of presentation to the clinic for HIV care were examined using a two-part study tool. The two parts consisted of a structured questionnaire and an ethnographic life history interview to obtain both quantitative and qualitative data. In the first part, a standardized study questionnaire was used to obtain quantifiable patient information. The questionnaire elicited patient demographic information, CD4 counts, symptoms at presentation, socioeconomic status, education level, distance from the clinic and other information about patient access to care. Some of these questions were guided by prior knowledge of the circumstances in rural Haiti, and in the central plateau in particular (see appendix 1 for questionnaire).

The second part of the research tool was aimed at obtaining the qualitative data that would help explain why patients presented at a particular time for HIV care. It consisted of open-ended questions embedded in a complementary ethnographic interview. This part elucidated the patient's personal story leading up to their HIV diagnosis and presentation to care. In this section, patients were asked to describe their childhood and family background; their living conditions growing up and their current

socioeconomic situation. The patients were encouraged to talk in detail about the circumstances surrounding their initial contact with the hospital, and to characterize any prior experiences they had had with Haiti's health care system. They were asked about their personal experiences, and beliefs regarding HIV disease, and about their understanding of HIV.

Each patient interview lasted between 30 to 90 minutes. All interviews were conducted by the author who is fluent in the patients' native tongue Haitian Creole, and were carried out privately either on the hospital grounds or in the patient's home environment. Memos, diagrams as well as field notes were kept during the course of the study. Individual transcripts of each patient encounter were kept, translated into English and are available for viewing.

d. Quantitative analysis

Data were entered in a Microsoft Excel spread sheet version 2000. The data were analyzed using Statistical Analytical System [15] version 8.2. Data were made binary and categorized based on CD4 cell count at patient's time of presentation. Time of presentation was defined as early if CD4 count was greater than or equal to 350 cells/mm^3 or late if CD4 cells were below 350 cells/mm^3. As HIV disease progresses, CD4 cell count diminishes such that lower CD4 cell counts are associated with more advanced disease. 350 cells/mm^3 was chosen as a cut off since in our clinical practice, patients with CD4 cell counts below 350 cells/mm^3 are considered sufficiently immunocompromised to merit antiretroviral therapy.

In order to assess the association between the specific measures (patient gender, age, education level, socioeconomic status, and distance from the clinic) and time of patient presentation (early with CD4 count at or above 350 cells/mm^3 or late with CD4 count below 350 cells/mm^3), the chi-square test was used. In the cases where the expected patient cell counts were less than 5, Fisher's exact test was employed. In all analysis, a p-value less than 0.05 was considered statistically significant.

e. Qualitative analysis

Each patient interview was tape recorded, transcribed, and translated from Haitian Creole into English by the author. The analysis of ethnographic data used standard qualitative analysis methods [14] to identify content and theme in the data set. This process included line-by-line examination of the data, followed by open coding to identify central concepts, and categories; axial coding to relate these categories to sub-subcategories and their dimensions; and finally integration of all the categories into a theoretical scheme through selective coding. Hypotheses were refined to help clarify the factors that lead some patients to present to clinic late in their HIV disease process.

IV. RESULTS

a. Quantitative results

General socio-demographic characteristics of the patient population

In this study of HIV-infected patients from central Haiti, 52% were male and 48% female. The mean age among the group was 39.5 ± SD 14 years (range 18-70). The mean number of years of schooling was 3.2 (range of 0-11). Only 19 % of the patients had reached a high school level of education and were literate. The majority (81%) either had never gone to school or reached a minimal level of education. Sixty-eight percent lived in dire poverty in thatched or mud houses without bath or kitchen. Seventy-seven percent of these patients worked as peasant farmers or unskilled laborers making less than the equivalent of 5 USD weekly. Fifty-five percent cited cost as a barrier to obtaining medical care in previous health encounters. Almost half (48%) of the patients had never been to a medical doctor before their exposure to PIH, while the 45% that had visited a local clinic for a prior medical concern, described their experiences as 'negative'. In their situations of poverty, 45% of the patients experienced the death of a spouse, and 61 % were more concerned about their daily survival than about their HIV-positive status (see table 1 for socioeconomic and demographic characteristics of this patient population and table 2 for a list of patient occupations).

In light of the high HIV burden of the population, 87% were aware that HIV could be sexually transmitted but 29% also had other non-medical conceptions about how HIV is transmitted. Only 16% were aware of their personal HIV risk factors, and even fewer 3% thought of HIV when they became symptomatic. Ninety-six percent of these patients had a history of living in Haiti's capital city, Port-au-Prince, where HIV is

known to be more prevalent [1], or had a partner who traveled to Port-au-Prince. Seventy-four percent lived within a two-hour walk from the nearest health clinic (see table 1 for additional information on patient access to care).

Population characteristics stratified by CD4 cell count at presentation

The majority (65%) of the patients in this study presented to the hospital for the first time for HIV testing diagnosis and care with advanced immunosupression when their CD4 counts were below 350 cells/mm^3. Median CD4 cell count at presentation for the late presenters was 189 cells/mm^3 (range 4–347), and 518 cells/mm^3 for the early presenters (range of 439–1104). To examine factors associated with the late presentation for HIV care among the patients, the group was divided into two: those who presented early with CD4 at or above 350 cells/mm^3 and those who presented late with CD4 below 350 cells/mm^3.

In this study, several factors were found to be significantly associated with late presentation for HIV care. First, patients' living condition, a marker of their socioeconomic status, was associated with late presentation for HIV care. Eighty-five percent of the late presenters reported living in thatched housing made of mud without latrines or kitchen while only 36% of the early presenters reported this and the difference was statistically significant ($p<0.02$). Patients who lived more than two hours away from the nearest clinic tended to present later for HIV care compared to those who lived within a two-hour walk from the nearest clinic. All of the patients who lived farther than two hours from the clinic presented late for care, compared to 48% of those who lived within two hours of the clinie ($p<0.005$). Older age was associated with later presentation for

HIV care. The mean age for the late presenters was 43.3 ± 15, compared to a mean age of 32.6 ± 10 for the early presenting group. The association between older age and late time of presentation was statistically significant ($p<0.05$). Finally, patients who had *not* received medical care at Zanmi Lasante, a PIH health care center, were more likely to present late for HIV care. Patients who reported receiving prior medical care at Cange, a PIH tertiary care center, presented earlier than those who had never been to Cange for care. Eighty-five percent of the late presenters had never been to Zanmi Lasante compared to 45% of the early presenters ($p<0.04$) (see table 3 for patient variables stratified by CD4 count at presentation).

Quantitative results tables

Table 1. General characteristics of the rural HIV-infected Haitian patient study population (N=31)

Variable	N (%)
Patient demographics	
Age*	39.5 ± 14
Gender	
Male	16 (51 %)
Female	15 (48 %)
Level of Education	
No education	8 (26 %)
1st to 5th grade	15 (48 %)
6th to 8th grade	2 (6 %)
High school level	6 (19 %)
Occupation	
Unskilled laborers and farmers	24 (77 %)
Skilled workers	7 (23 %)
Living Condition	
Good (cement & block house with latrine)	10 (32 %)
Bad (thatched/mud house, no latrine)	21 (68 %)
Timing of presentation	
Early (with CD4 count >= 350 cells/mm^3)	11 (35 %)
Late (with CD4 count < 350 cells/mm^3)	20 (65 %)
Access to care	
Distance from local clinic	
0-2 hours away	24 (74 %)
> 2 hours away	7 (23 %)
Expressed cost as a barrier to care	
Yes	17 (55 %)
No	14 (45 %)
Prior experience with local hospitals	
Never been to the doctor before contact with PIH at St. Therese Hospital	15 (48 %)
Had been to a local hospital before	16 (52 %)
Patient impression of the local health care system	
Positive	2 (6 %)
Negative	14 (45 %)
Ambivalent	15 (48 %)

Patient HIV Knowledge & risk factors	
Aware that HIV is sexually transmitted	
Yes	27 (87 %)
No	4(13 %)
Aware of personal HIV risk factors	
Yes	5 (16 %)
No	26 (84 %)
Thought of HIV when became symptomatic	
Yes	1 (3 %)
No	30 (97 %)
Hold non –medical conceptions about HIV transmission[A]	
Yes	9 (29 %)
No	22 (75 %)
Lived in Port au Prince or had sexual partner who traveled to Port-au-Prince[B]	
Yes	29 (96 %)
No	2 (6 %)
Lost a spouse to illness suggesting HIV/AIDS	
Yes	12 (39 %)
No	19 (61 %)
Concern about poverty outweighs HIV concerns	
Yes	13 (42 %)
No	18 (58 %)

*Values are mean ± SD

[A]See table 5 for list of patient conceptions about HIV transmission

[B] The risk of obtaining HIV increases with travel to Haiti's capital Port-au-Prince where the HIV prevalence is 5.7 % [1].

Table 2. Occupations of study patient population

Variables	N (%)
Male patient occupations	
Peasant farmers / Sharecroppers	7 (23 %)
Laborers (construction work, loading and unloading cars, carts)	4 (13 %)
Artist	1 (3 %)
Electrician	2 (6 %)
Bus driver	1 (3 %)
Carpenter	1 (3 %)
Female patient occupations	
Market women (selling foods stuff, fruits, rice, oil; charcoal)	7 (23 %)
Domestic servants	4 (13 %)
Farmer	1 (3 %)
Cloth washer	1 (3 %)
Seamstress	1 (3 %)
Restaurant cook	1 (3 %)

Table 3. Descriptive Statistics for the study population stratified by CD4 count at presentation (N = 31).

Variable	CD4<350 N (%)	CD4≥350 N (%)	P-value
Age *	43.3 ± 15	32.6 ± 10	0.045[A]
Gender			
Male	12 (60 %)	4 (36 %)	0.208
Female	8 (40 %)	7 (64 %)	
Level of Education			
Some Education	14 (57 %)	9 (78 %)	0.676[B]
No Education	6 (43 %)	2 (22 %)	
Living Condition			
Good (cement & block house with latrine)	3 (15 %)	7 (65 %)	0.013[B]
Bad (thatched/mud house, no latrine)	17 (85%)	4 (36 %)	
Distance from local clinic			
0-2 hours away	10 (48 %)	11 (52 %)	0.0049
> 2 hours away	10 (100 %)	0 (0 %)	
Believe illness is of magical origin			
Yes	7 (78 %)	2 (22 %)	0.429
No	13 (59 %)	9 (41 %)	
Received prior medical care at Cange or other PIH / Zanmi Lasante clinic			
Yes	3 (15 %)	6 (55 %)	0.038
No	17 (85 %)	5 (45 %)	

*Values are mean ± SD

[A]P values were obtained from Student's T-Test

[B]P values were obtained from Fisher's exact test.

b. Qualitative Results

Factors associated with the delay in presentation for HIV care

Once symptomatic, patient care seeking behavior appears to be associated with variables linked to the poverty of the patients: poor patient general education and HIV knowledge; belief that symptoms are not caused by a medical condition; low socioeconomic status and lack of prior access to free and effective medical care; and prior negative experience at local hospitals. These four major categories of influential factors are themselves based on patients' experiences, and personal belief system (see table 5 for Intra-personal and environmental factors that influence timing of patient presentation to care).

Patient symptoms and knowledge about HIV

More than half of the patients (55%) presented to the clinic with symptoms of fever and night sweats for more than one month. Fifty-two percent presented after loosing greater than 10% of their body weight. Thirthy-two percent had diarrhea and 19 % had zoster (see figure 4 for distribution of patient symptoms at presentation and table 4 for a detailed list of patient CD4 count and symptoms at presentation to the hospital). Despite these presenting symptoms, many patients were unaware of the severity of their disease. Fifty-two percent thought their illness was *not* serious. Only 3% thought at presentation that their symptoms might be related to HIV. The patients interviewed had inadequate information about HIV, 29% held non-medical conceptions about how the disease is transmitted. While 39% had taken care of partners who died with symptoms suggestive of AIDS, *none* of the widowed patients thought they might have been exposed to HIV (see

table 6 for patient thoughts about their symptoms and their HIV transmission knowledge).

Intra-personal influences of timing of presentation

Patient belief systems about their disease played a major role in the timing of their presentation to care. Fifty-nine percent of those who presented late also believed that their disease was caused by super-natural causes based on the explanatory models of Voodoo one of the official religions in Haiti. These patients delayed going to the doctor while they received treatments from a male traditional healer or *hougan*. Only 23% of the early presenters held such beliefs. Those who sought *hougan* help spent an average of two years (range 6 months to 7 years) following the *hougan* treatment before deciding to go to the hospital (see table 7 for information on patient Voodoo beliefs).

Patients' prior experiences with the local health care system and the related personal beliefs about the quality of care offered at the hospitals played a role in the timing of their presentation. Ninety-five percent of the late presenters either had a negative prior experience with a local hospital, or were ambivalent to hospital care. Forty-five percent avoided the local clinic because of a negative impression of the clinic: some feared that a harmful event might occur if they went to the hospital; others had received ineffective treatments or did not receive adequate information when they went to the hospital (see table 8 for a complete list of patient experiences that shaped their perceptions of the local health care system).

For many patients who become sick, going the hospital is a last resort; patients come in contact with the hospital when all else fails. Ninety-seven percent had tried home

remedies first when they became symptomatic, and went to the doctor only after these remedies had failed. Twenty-three percent came in because they were encouraged or forced to do so by family and friends; 19% were identified in the communities and brought in the clinic by PIH community health workers. Twenty-six percent came in to St. Thérèse hospital because they heard that the Zanmi Lasante or Cange doctors were there (see table 9 for circumstances surrounding patients' first hospital presentation for HIV care).

Qualitative Results Tables

Table 4. CD4 cell counts and symptoms of patient study population at first presentation for HIV care at the Hospital St. Thérèse.

Patient #	Age	Gender	CD4 count (cells/mm^3)	Fever >1 month	Night sweats	> 10% weight loss	Diarrhea for > 1 month	Other symptoms	Prior HIV Diagnosis†
Early presenters									
5	18	F	439			X	X		
7	22	F	515		X			Cough >1month	
10	23	F	1104					Mennorrhagia	
17	35	F	762	X	X	X	X		
14	37	F	518	X	X				
15	46	F	666					Pruritus, rash	
4	48	F	471					LAN*dysphagia	
16	26	M	469					Zoster, LAN	
13	33	M	539	X	X				
8	35	M	545	X				Abdominal pain, dysphagia	
18	36	M	448	X			X	Zoster	
Late presenters									
27	26	F	198	X	X	X	X		
29	27	F	294	X	X	X			
31	28	F	138			X			
9	34	F	194	X	X				
30	40	F	8	X	X	X	X	Zoster, pruritus	
24	44	F	291	X	X				
3	45	F	337					Zoster, pruritus	
1	70	F	264	X	X	X		Zoster	
11	24	M	4	X	X	X	X	Oral thrush, cough>1month	
22	30	M	347	X	X	X		Cough>1month	X
26	31	M	45	X	X	X		Cough>1month	
28	32	M	120	X	X	X	X	LAN	
25	34	M	94	X	X				
20	49	M	281	X	X	X	X	Zoster,	
12	50	M	13	X	X	X	X	LAN, cough>1month	
23	50	M	221	X	X	X	X	dyspnea	
2	55	M	184	X	X	X		Oral thrush, dysphagia	
6	57	M	63			X		Oral thrush, hemiparesis, skin rash	
21	69	M	81	X	X	X	X	Cough>1month	
19	70	M	333	X		X		Oral thrush	

†Patients carrying HIV diagnosis prior to presentation for care at PIH / ZL clinic
LAN= Lymphadenopathy

Table 5. Environmental and Intra-personal factors that influence the timing of presentation for HIV care. (N=31)

Variables	N (%)
Environmental factors	
Patients lacking appropriate education / knowledge about HIV	26 (84 %)
Lack access to good medical care	17 (55 %)
Intra-personal factors	
Patient belief that illness is of magical origin	9 (29 %)
Patient with negative thoughts of local hospitals and clinics	11 (35 %)

Table 6. Patient thoughts about their symptoms and HIV transmission (N=31)

Variables	N (%)
Patient thoughts about the cause of their symptoms	
Thought it was a non serious illness/gas/rash	16 (52 %)
Thought it was magical and 'sent' to patient	9 (29 %)
No thoughts / ideas	4 (13 %)
HIV	1 (3 %)
Typhoid	1 (3 %)
Patients non-medical conceptions about HIV transmission	
HIV can be transmitted by sharing food	3 (9 %)
By stepping over contaminated sputum	3 (9 %)
By shaking hands	1(3 %)
Through an animal bite	1(3 %)
Through sharing of a chair	1(3 %)
Total	9 (29 %)

Table 7. Patients traditional beliefs about origin of disease

Variable	N (%)
Patients who believe disease is magical	9 (29 %)
Proportion who sought and obtained hougan treatments	7 (23 %)
Expressed relief from hougan treatments	3 (10 %)
Disappointed or had no relief from hougan treatments	4 (13 %)

Table 8. Patient perceptions of local health care system and prior experience with the hospital

Variable	N (%)
Hospital as the last resort	
Tried other remedies before going to the hospital (Home teas, boiled roots, market pills injections)	30 (97 %)
Went to the hospital only after these remedies failed	30 (97 %)

Characteristics of negative experiences at the hospital	
Medications/ treatments given were ineffective	5 (16 %)
Patient was turned away for lack of money	5 (16%)
Fear 'harmful' event might occur to them at the hospital	3 (10 %)
Did not obtain appropriate information about illness	3 (10 %)
Did not like service of hospital staff	2 (6 %)

Table 9. Circumstance around patient contact with the hospital

Variable	N(%)
Answers to what would have brought patients to the clinic in earlier	
If patient knew what the symptoms meant	5 (16%)
If patient had money	14 (45%)
Don't know	12 (39%)
Why patients came into the hospital	
Did not get better on local remedies/condition worsened	30 (97%)
Were encouraged/forced to come in by family/neighbor/friend	7 (23%)
Were picked up by ZL community health workers	6 (19%)
Heard that Cange doctors were at the St. Thérèse clinic	8 (26%)

V. DISCUSSION

The purpose of this study was to determine the factors associated with the late presentation for HIV care among patients in Hinche, Haiti. Intra-personal factors such as patient gender, age, and belief system about their disease, as well as socioeconomic factors, patient distance from the clinic and previous experience with the local hospitals will be discussed in terms of their influence on the timing of patient presentation for HIV care.

PART 1. THE CONTEXT: PATIENT BACKGROUND

a. Patients' socioeconomic background

All of the patients interviewed grew up poor in rural Haiti and are for the most part, children of peasants whose livelihood consisted of subsistence farming and other forms of manual labor. Most of the patients grew up in typical peasant houses made with woven wood walls, dry palm leaves on the roofs and dirt floor without bathroom or kitchen (see figure 5 for an example of a peasant house in Haiti's central plateau). These houses were usually full of people. Twelve siblings, for example, surrounded patient 2 when he was growing up, and in patient 3's family, they were 8 sharing a one-room hut. From childhood most have had no exposure to health care in their rural settings, and when many of these patients became sick, their parents relied on their own knowledge of herbs and on local healers for remedies and cure.

b. Patients' educational background

In this impoverished setting, the level of ignorance is extreme. Basic education in general is very limited, and access to secondary education in Hinche is almost non-existent. The majority of the schools are private and most peasant families are unable to pay the fees required to send their children to school. Those who do make it to school often only reach a primary level of education; rarely do they make it to high school. Out of the 31 patients interviewed, 19% had reached the high school level but none had completed high school; the remaining 81% were illiterate having had zero to just a few years of schooling. The severe lack of even basic education can translate into very low level of knowledge about HIV disease, and this ignorance can play a role in a patient's HIV risk.

c. Patients' work and livelihood

Physical labor as work for the poor and uneducated

Those patients who went the furthest in school, whether their parents were peasant farmers or not, were on average able to find better jobs than those who did not go to school at all. The relatively educated patients of the group, those who were able to make it to high school, held jobs that were more economically rewarding and stable. These individuals were likely to have learned a trade, learned how to drive, or developed a special skill. The professions among the relatively educated in the group included a bus driver, an electrician, an artist, a mason and a restaurant cook. Patient 6, a 57-year-old man, who had reached the ninth grade, learned how to drive and became a bus driver in Port-au-Prince making the equivalent of 71 to 85 USD a week. Patient 12, a 50-year-old

man, reached the 11th grade and then took some courses to become an electrician. He found rewarding work in the capital. Patient 18, a 36-year-old man, who also reached the 11th grade honed his wood carving skills and sold his carved wood art pieces in Port-au-Prince making up to the equivalent of 1500 USD in a month. These individuals were able to make a relatively comfortable living with their job income. They enjoyed an economic freedom few peasants ever see, and they are not dependent on others for their survival as is often the case for illiterate peasant farmers and unskilled laborers.

Without adequate education or a special skill, the peasant has very little with which to bargain and the ability to gain a livelihood becomes intimately tied to physical capability. This is unfortunately the case for 81% of the patients interviewed. Whether in the rural towns, or in Haiti's cities and capital, the peasant's best and most precious asset is physical labor. In the rural setting this labor consists of farming which is the most common occupation of the poor in and around Hinche. This activity is subsistence farming or sharecropping where the peasants toil away in patches of infertile soil on Haiti's eroded mountain- sides. This is not large-scale, industry driven, and machinery supported farming; rather we're talking about a single man or woman, plotting land with makeshift or rudimentary tools, in a labor-intensive penance that is often fruitless and unpredictable.

Eight of the patients interviewed described themselves as farmers, all men and one woman. When they worked, they rented land from a neighbor or simply worked in someone else's land if they did not own a garden. None of the people interviewed participated in an organized, group farming activity. They all worked alone and each made on average less than the equivalent of 1 USD a day. How much money would a

farmer make in a month? *"It varies,"* responds patient 1, a 70-year-old woman, *"Sometimes we get food, coffee, or a few gourdes, and some days we get nothing."* Patient 2, a 55-year-old man, explains that a full day of farming can bring in 50 gourdes (about 1.6 USD), giving credit to the statistics that 55% of Haitians live on about 1 USD a day [8].

Women's work

The women without education or skill and who do not work the land are likely to end up as market vendors or domestic servants. Thirteen of the 15 women interviewed fell in that bracket. A market woman can sell anything; fruits from a garden; cooking items like rice, oil, or peas; cloth for uniforms, various household goods, or even charcoal -Haiti's number one fuel source, obtained by burning the county's scarce remaining wood. In fact market women are quite numerous in the country and commerce is more a subsistence way of life than it is a profitable business.

The market women interviewed made variable gains from their businesses. Patient 7, a 22-year-old woman, buys *quenneppes* (a fruit) in large quantities for 50 gourdes; when she resells them, she profits 25 gourdes (about 80 US cents) a week. In her setting, the profit would not feed her for the week unless she has access to other resources. For those who are able to keep track of their gains, the profits once tabulated are barely enough to allow survival. But most market women do not keep track of their profits because like Patient 4, a 48-year-old woman, who makes a living selling rice and corn, they eat from the business daily. As the women continue to live off the profits daily, the commerce comes to an end and they are left without any money to start the business

over again. It is important to note that while it has been found that economically disadvantaged women often enter commercial prostitution as a way to survive, this was not found to be the case among the women in this study.

Travel to the capital in search of work

Those without skills and education who decide to leave rural Haiti and make their livelihood in the city also face doing manual labor for a living. They are likely to labor in the city's markets as load carriers, produce transporters, or do low skill jobs like selling bread on the streets. The men and women who left their rural towns without education or skills to go to Port-au-Prince became laborers and domestic servants. Four of the five women who went to Port-au-Prince worked as domestic servants. Patient 16, a 26-year-old man, carried loads for people in Port-au-Prince, and patient 25, a 34-year-old man, carried loaves of bread to sell at the market for a local bakery.

With the move to the capital and local cities, the farmlands are left behind deserted and uncultivated. Many of the interviewees, like patient 2, have family land that could be cultivated, but because of their move to Hinche or to the capital, the patients are too far away to work these lands. Patient 5, an 18-year-old female, states that her family has land in her rural town, but now that everyone has moved to Hinche no one takes care of that land. The land abandonment resulting from migration to the cities leads to reduced food production, which does nothing to alleviate local hunger and misery of the population.

Unfortunately, the move to the country's capital does not improve the economic situation for the majority of peasants who move there. Despite all the efforts of moving

away and laboring, most remain in misery and don't make it far above the economic status of their parents. The jobs that they find simply do not make life easier and in fact many complain that life in the city is more difficult than the rural life. Often the houses that they move into are in far worse condition than the ones they leave behind in their villages. The few who learn a trade rely less on their manual labor, and are able to reach a relative economic stability that the city laborers and peasant farmers can only dream of.

PART 2. PATIENT HIV RISK FACTORS: How socioeconomic status, education level and work shape patients HIV risk in Haiti

a. General HIV risk factors in Haiti

Risk factors for HIV in Haiti include heterosexual contact or marriage to an individual who works or travels to Port-au-Prince where the HIV prevalence is much higher; and is shaped by social factors such as low socioeconomic status which drives many to travel to Port-au-Prince, or take partners for economic survival thereby increasing their HIV risk [16,17]. Drug use and homosexuality are *not* significant HIV risk factors for this population.

When asked what factors contributed most to bringing them to their current life situations, participants of this study answered that *"misery"* or *"poverty"* had led them to their current states. For people who live in poverty in Haiti, economic need shapes their HIV risk factors. Patient 14 explains *"I would not be HIV positive and in this situation, if I did not have to take a third husband."* This scenario of a woman, who accepts a husband because of economic necessity and ends up with HIV, unfortunately repeats itself in Hinche and the surrounding rural towns of Haiti's central plateau. To understand

how economic need drives the risk of acquiring HIV among these patients, it is useful to look at the patients' socio-economic lives as context for their HIV risk.

It has been shown that the prevalence of HIV infection in Haiti is inversely associated with socioeconomic status [16]. This risk factor for HIV is at play in this study where the majority of the patient population is of a relatively low socioeconomic status, and had either lived in Port-au-Prince or had a partner who worked in Port-au-Prince. Many of the peasants in the rural setting by virtue of being uneducated, were without skills that could help them obtain a good job. Those who traveled to the capital in search of a better life instantly increased their HIV risk. For the relatively educated men of the group, it is the very fact they have a skill that brings them to the capital thereby increasing their HIV risk. As electricians, army men and artists, they moved to the capital where they would be employed and well compensated.

Travel to Port-au-Prince as part of a job increases men's and women's risk of HIV [16,17]. In this study, just five women had traveled to Port-au-Prince, four went to work as domestic servants. All of these women returned to their rural homes HIV-infected, and in worse economie condition. Patient 5 for example, an 18-year-old girl, was given away as a domestic servant to a family in Port-au-Prince at the age of fourteen. She became pregnant at age fifteen and the father of the child died of an unknown disease. She left Port-au-Prince at the age of sixteen and returned to Hinche, where she was found to be HIV-positive. This scenario is not uncommon for many of the young women who leave their rural towns to go work in Port-au-Prince.

b. HIV risk factors for women in rural Haiti

The HIV epidemic which is spreading mainly via heterosexual contact in Haiti, is affecting almost as many women as it affects men [1,21]. Most of the women in this study were exposed to HIV through economic dependence on a partner who traveled or worked in Port-au-Prince. Studies done in Africa and in India have shown marriage to be the greatest HIV risk factor for some women, and other studies have shown that women who were economically vulnerable and reliant on a partner for income, were at higher risk of sexually transmitted diseases [18]. Likewise in this study, many of the women who struggle financially and take economically stable partners, increase their risk of acquiring HIV. This is because the husbands, who are able to provide for the women and their families, often work in or travel to Port-au-Prince where the HIV prevalence is higher.

All of the women reported moving only once or twice during their lifetimes, going mostly from their parents' homes directly into their husbands' houses. Out of the fifteen women interviewed, 10 had never left their local area, they either remained in their rural towns, or moved to nearby Hinche; only 5 women had been to Port-au-Prince to work. Lack of geographie movement to the capital where HIV prevalence is higher unfortunately does not shield women from the HIV risk. The disease readily comes to them via partners who return home after working for periods of time in Port-au-Prince.

Sex with multiple partners, which has been found to be an HIV risk factor in other female populations, was *not* a major factor in this group. All of the women in this study reported having had between one and three total lifetime sexual partners. Sixty percent had had two consecutive partners during their lifetime, 33% had only been with their

current partner and 7% were with their third partner. This suggests that promiscuity is not as significant as marriage and economic vulnerability in shaping women's HIV risk in rural Haiti. Patient 3, a 45-year-old woman, shares what she thought helped to bring her to her present situation:

> *"The guy I was with was a "vagabond" (promiscuous) he was in the Haitian army and I don't know what he could have done. I have not been with anyone else."*
>
> *Patient 4, a 48 year-old woman: "I have not been with many people, my husband was a good looking man and women were into him."*
>
> *Patient 15, a 46 year-old woman: "I have seven children. I had the first two with my first partner. He was in the Haitian army. He became sick, lost weight and died. After my first two children I was alone. I was trying to find a way to help myself with the first two children and that is how I got the others. My third child was for a married man. He was a tailor and his wife was in Canada. He built a small house for me, I had two children for him and he became sick in my hands. I took care of him until he died. When he died, I did not get anything from what he had."*
>
> *Patient 14, a 37-year-old woman: "Overall it is the type of life that I have had that put me where I am today. The lack of possibilities. I have five children and no one to help me. I was working as a domestic and while there, I met the man who told me that he would take me out of working as a domestic. That is how I got the second child. He did not take any of his responsibilities. I was pregnant with the second child when I met my third partner. He saw that I was alone, pregnant and with one child. He talked to me and I accepted him and we started a life together. He took my two kids and we had three more children. I say if God had given me the means after the second child, I would never have taken another man, and there are some things that I would never find myself in at all. I think if it is possible that I have this sickness (HIV), without a doubt it is from my last partner."*

These quotes illustrate the interaction between women's economic dependence, partnering, and their HIV risk. *For a poor woman in rural Haiti, economic dependence on a man who can provide for her family is intimately tied to her risk of getting HIV.* The men who provide the economic stability, travel to the capital where the HIV prevalence is higher, are sought after by other women in need of economic stability, and are not always

faithful when they travel. Their behavior is more likely to predict whether their wives become infected with the HIV virus.

PART 3. WHEN POVERTY MEETS DISEASE: what happens when these patients become symptomatic

a. Loss of livelihood

For the poor and uneducated, a strong and healthy body is their only possession. Their efforts, physical strength and time represent the assets and tools to survive. When disease cripples the body and there is no other plan to fall back on, survival is tested and the patient becomes dependent on the charity and goodwill of others. Patient 2, a 55-year-old male farmer, complains: *"I used to work the land, but now that I am sick I cannot make any money."* Patient 8, a 35-year-old man, made a living fixing cars until he got sick and lost his physical strength. Becoming symptomatic greatly affects the lives of the farmers and laborers who depend on their physical aptitude.

How do farmers make a living when they are diseased and cannot labor? They ask for money and eat from charitable neighbors. As one patient explains he *"sometimes goes to ask for money in the market"* and when begging does not bring relief, they 'endure'. For some patients it is customary to have days during which they do not eat at all. *"Some days we suffer"* states patient 1, the 70-year-old woman, which means that *"some days we don't eat at all."* This situation happens so frequently that patients have developed coping strategies for survival when they are 'suffering' or not eating. On these days, explains patient 1 *"I suck on a grain of salt, find some water to drink, and lie on my belly. I talk to God who then gives me sleep. That's how your child is living."* Day – long

forced fasting occurs with such frequency that it has necessitated a concrete coping strategy. Such is an example of the degree of poverty that makes up the context for the HIV epidemic in rural Haiti.

For non-farmers and non-laborers who are inflicted with disease, though their livelihood may not directly be affected by a decrease in their physical capabilities, the disease makes them suffer in a different manner. For women who depend on some cash flow to carry on with a little commerce, getting sick could mean spending the little that they have in local remedies. For patient 6, who was a relatively well off electrician, the disease dried out his savings and forced him out of his livelihood. The entire household became vulnerable financially, and his wife had to stop her activities to take care of him and their five children.

b. Appropriate medical care is delayed as patients try home remedies

Before any contact with the hospital, what happens when the patients become symptomatic or feel sick? The findings of this study suggest that patients do not rush to visit doctors. Most of the patients, 65%, presented to the hospital when their CD4 counts were below 350 cells/mm^3. The fact that most patients in this study presented late for their initial care, is consistent with observations by Ivers who noted that in Haiti's central plateau the majority of HIV patients, presented late at their first HIV clinic visit [9].

While it is impossible to determine exactly the length of time a patient has spent with HIV, the CD4 count represents the best available laboratory tool to determine the stage of disease in HIV patients. Though imperfect as a marker of HIV disease duration, and variable between individuals, the CD4 count, which is normally above 800 cells/mm^3

in immuno-competent persons, can be used to estimate the length of time a person has been infected with HIV. It has been shown to decrease by 60 cells/mm^3 on average per year in HIV infected homosexual and bisexual men [19]. Based on this observation, time spent with the HIV virus among this cohort of patients was estimated to range between 0.6 to 13.3 years. Patients spent an average of eight years with the virus before ever obtaining appropriate medical help.

The following is the sequence of events that occurs with many of the interviewed patients when they became symptomatic with fever and night sweats for more than a month, weight loss, diarrhea and other symptoms. All groups seem to try home remedies of teas or syrups made from various leaf extracts and other herbal treatments first -before going to the doctors. If these measures fail, some call on traditional healers to lay hands on them or give them injections, usually of antibiotics. When the home teas and local healers fail, some, usually the younger patients, buy pills from the market, frequently analgesics for symptom relief. As the symptoms progress and patient interventions fail, those who believe that their relentless symptoms are Voodoo related seek help from traditional healers or *hougans*, and those without supernatural beliefs seek medical help at a hospital or clinic.

PART 4. FACTORS ASSOCIATED WITH LATE PRESENTATION FOR HIV CARE

What is keeping the patients away from care for so long? According to this study, the factors associated with the late presentation for HIV care can be divided into two categories: socio-economic and intra-personal factors. Socio-economic factors include

the patient basic education and general knowledge about HIV, socioeconomic status as it relates to access to medical care, as well as patient home distance from the hospital. The intra-personal factors which include patient gender, age, personal belief system about the origin of their disease, as well as personal perceptions of the local health care system, all affect patient decision as to when to present to care.

1. Socio-Economic Factors

a. Lack of basic education, poor HIV knowledge and timing of presentation to care

Most of the patients interviewed were illiterate. Both groups, early and late presenters had on average just 3.2 total years of schooling. However 32% of the late presenters compared to 18% of the early presenters had never been to school. Though the association was not statistically significant, the proportions suggest that severe lack of education is a possible component of the factors that keep peasants away from care early in their disease processes. With lack of education patients are likely to have reduced knowledge about their HIV risk factors. These patients are less likely to understand public health messages about HIV since the available information may be in the form of flyers and books requiring a certain level of education for comprehension, therefore inadequate for the majority of rural Haitians.

Patient knowledge about HIV varies from having never heard of HIV/AIDS to knowing a fair amount about the disease risk actors, mode of transmission and symptoms. While most people had heard about AIDS, very few patients knew about the relationship between HIV and AIDS.

The lack of adequate education about HIV makes it more difficult for patients to identify potentially serious symptoms associated with HIV. Of the six patients who presented with zoster, for example, not one of them thought that perhaps the zoster could be related to HIV. Only 13% of the entire group expressed appropriate medical knowledge about HIV transmission, symptoms and ways to protect oneself against the virus. The remaining 87% of the patients either knew nothing about the virus or had a limited knowledge about the disease. When patients lack of knowledge about HIV/AIDS symptoms their suspicion for the disease is low and this could translate into delayed presentation for care.

Patients are unaware of the severity and meaning of their own symptoms

Patient 30 for example, a 40-year-old widow, whose husband had died of an unknown illness, presented to the clinic with a CD4 count of 8 cells/mm^3. "What were your symptoms?" She was asked. *"I felt a fever and headache, I had a zoster that broke out on my left eye and I had diarrhea."* "What did you think you had?" *"I didn't think I had anything."* Patient 6, a 57-year-old man who presented with CD4 count of 64 cells/mm^3 had experienced a generalized rash and had lost greater than 10% of his body weight at presentation: *"I never thought I had anything"* he shared, when asked about his symptoms. Patient 11, a 24-year-old man, who presented with oral thrush, diarrhea, fever and weight loss, had a CD4 count of 4 cells/mm^3 at presentation. He explains what he thought of his symptoms: *"I did not think anything of it, when you are sick you can't think of what it could be, so I never had any ideas of what I had."* Over half of the patients in this study suffered from fevers and night sweats for more than a month, and

had lost more than 10% body weight when they presented. One third of them had diarrhea and almost a quarter had an outbreak of zoster. Most of these patients did not think their symptoms were serious, suggesting both a high threshold for suffering and little sensitivity to alerting health symptoms.

"I did not know my sickness was a hospital disease, If I knew I had a 'doctor's disease' (an organic, non-magical disease) I would have gone earlier" says patient 26, a 31-year-old man who presented for HIV care with a CD4 count of 45 cells/mm^3. Patient 1, a 70-year-old woman, had a zoster outbreak encompassing the entire left side of her body. She endured this painful zoster for five months all the while seeking traditional help for the pain caused by the zoster. She never knew the severity of her situation, and never associated her zoster with HIV. Patient 3, a 45-year-old female, remained symptomatic for two years experiencing fever, swollen leg and zoster. When asked what she knew about HIV she answered: *"I don't know anything about it, I don't have a radio. I sometimes hear about it."* Even while suffering with fever, night sweats, diarrhea, weight loss, and zoster, if the patients don't know what those signs could mean HIV, their presentation to care could still be delayed, underlining the importance of appropriate HIV education. Only two of the patients interviewed thought that they might have HIV when they first presented to the hospital for care.

Patients don't recognize their exposure to HIV or their HIV risk factors

Whether due to disease, misery, or a combination of both, death is a very frequent occurrence among the poor in Hinche; it is common and tangible, and is reflected in the Haitian adult life expectaney of just 50 years [1]. Almost half of all the patients had lost a

partner to disease, the prevalence of partner death was 45% among those interviewed. Most of the patients who lost their partners were women; they had taken care of their ill and dying husbands. While it is difficult to say for certain how many of the spouses died of HIV related causes, the description of the partner's illness combined with the fact that they left behind HIV positive spouses, suggests that many were likely to have been affected by the virus.

Patient 5, an 18-year-old, lost the father of her first born child to an unknown illness. So did patient 9, a 34-year-old woman who relates that during his illness her husband became so thin that his cheeks were sticking out. He died after having lost most of his body weight. Patient 29, a 27-year-old woman, noticed that she started loosing weight while taking care of her husband who was dying. Her ill husband who was suffering with weight loss, diarrhea, and rashes, eventually died and she never associated his symptoms with HIV. When she herself begun to exhibit the same symptoms, HIV still did not come to mind. Patient 27, a woman of 26 years, also took care of an ill and dying husband. When asked: "Do you know what he died of?" she replied, *"I don't know, he was very sick, he was vomiting, he had diarrhea, he had a zoster and fever."* While most of the spouses died with illnesses suspicious for HIV, none of the widows thought the husbands might have had HIV. So lack of awareness about the symptoms of HIV disease is rampant even in cases where the patients live with and care for patients who die of AIDS. This lack of awareness about HIV among the patient population suggests the inadequacy of current public health messages. Those messages are either not reaching the group, or the individuals simply are not able to understand or access the messages.

It has been found that the heterosexual population is often unaware of their HIV risk factors [10]. Few of the patients interviewed were aware of their HIV risk factors. The lack of awareness about HIV risk factors is not surprising given the general lack of education among the population.

Patient held non-medical conceptions about HIV

In a setting where health education does not reach everyone, many non-medical conceptions exist about how HIV is transmitted, even when some understanding of HIV transmission exists. When patient 17, a 35-year-old female, is asked how she became infected with HIV, she explains: *"I feel like my second partner put me in this situation, he needed no excuse to go out and sleep with other women."* This answer suggests an understanding that HIV can be transmitted sexually. Yet when she is asked about how HIV is transmitted she replies: *"If someone with the disease stands up from a chair and someone else sits in that chair while it is still hot, that person can catch the disease."*

While 87% of the patients interviewed expressed an understanding that HIV can be sexually transmitted, many of them, 29%, had other conceptions about HIV transmission. Patient 10, a 23-year-old woman, who says *"When having sex, you can use a condom"* for protection against HIV, also believes that *"If someone spits and you walk in it you can get it."*

Other common non-medical conceptions about HIV transmission lie around the sharing of food. Patient 19, a 70-year-old man, is asked what he knows about HIV and answers, *"Well I know that if you share food with someone who has it you can catch it, if you step on someone's spit you can get it."* When asked how do you protect yourself

from HIV he replied: "I don't eat out" to avoid leftovers. *"I avoid other people's houses and I am with no one else but my wife."* In the same light, patient 21, a 69-year-old man who knows that he has HIV and wants to protect his children, warms them from eating his leftovers, *"I told the kids: look I'm sick, when you see my leftovers don't eat them."*

Patient 11, a 24-year-old man who was relatively educated and had reached high school, volunteered: *"An animal can bite someone and then bite someone else and transmit it."* Patient 6, a 57-year-old man who had also reached high school, no longer extends his hand in handshake. He believes HIV was transmitted to him via a handshake. Even though the majority of the patients conveyed an understanding that HIV is sexually transmitted, many explanatory models co-exist about HIV transmission and about patient personal risk factors for HIV.

The importance of HIV education

Some studies have suggested that a mean HIV transmission knowledge score of 80% [20] or more would be an appropriate level of knowledge among HIV positive patients in order to ensure prevention of HIV re-infection, and HIV transmission to partners. Although appropriate HIV transmission knowledge does not necessarily translate into safer individual behaviors, it remains a crucial and necessary step for the prevention of HIV [20]. A significant proportion of the patients interviewed demonstrated lack of appropriate HIV transmission knowledge. This was the case among those who were relatively educated and had reached high school, as well as among those who had never gone to school. Patients with this lack of knowledge may be at increased risk of re-infection and may transmit the virus to other partners.

Simply reaching a high school level of education in and of itself does *not* seem to make people present for care earlier. Most, or 89 %, of the patients who had reached high school were men, a group known to have the tendency to present late for care [10], and in this study, a group that also more often sought treatments from traditional healers, further delaying their medical care. So providing HIV specific education for the population is crucial. Ample access to accurate HIV-related information that is clear and comprehensible to the target population is important in order to reduce the risk of HIV transmission [20].

The lack of awareness among the patient population about HIV risk factors and signs of disease provides ample opportunity for HIV education. Perhaps if patients could recognize some of the symptoms of HIV or be aware of their risk factors, they would look for medical help earlier. Education of the patients on these points could be a focus of intervention to help prompt patients to come into the hospitals sooner.

b. Economics barriers and the timing of presentation to care

Although there were some relative economic differences among the patients interviewed, most belonged to the same socioeconomic group. Rather unsurprisingly, relatively poorer socio-economic status and living conditions were associated with later presentation to care ($p<0.02$). Eighty-five percent of those who presented to care late reported living in thatched and mud houses without bath or kitchen, while 36% of those who presented early reported this. Thirty-two percent of the HIV patients who presented late were peasant farmers or laborers compared to 18% of the early presenters. A

patient's living conditions will depend on his or her economic means. So lack of finances or level of poverty is a major determinant of timing of presentation.

Lack of finances as a barrier to medical care

Patient 1's journey to medical care is not uncommon in Hinche; she had never been to the doctor's in her life and had no concepts about the hospital. She became sick and tried the home remedies first -a reflex for many Haitian peasants. Then she got worse and wanted to go to the doctors. She went to the local clinic, but could not obtain care because she had no money to pay for the medical services. She heard about free good care available at Cange and wanted to go, but could not afford the cost of transportation to Cange. *"If you don't have money you cannot go. If I had money I would have gone to Cange earlier"* she confesses.

For the patients without financial means, barriers to medical care exist as fees for service at the clinic, or fees for transportation to the hospital in Cange that provides free services. Fifty-five percent of the patients cited cost of the hospital visit as a barrier to obtaining medical care. Before the arrival of Partners in Health (PIH) to St. Thérèse Hospital, all patients had to pay for their consultation, laboratory tests, as well as for any medications prescribed. These fees kept some patients from starting a contact with the health care system; they simply could not afford it. Patient 2, a 55-year-old man, recounts: *"In December 2003 I went to the hospital. When I went to the hospital, the Cange (PIH) doctors had not come yet, the prescriptions they gave me cost money. I didn't have any money. So they sent me to steal. I could not follow the treatment."* In this case as in many others, the patients are not consciously staying away from the doctors

and the healthcare system. This man sought medical help multiple times at the local clinic soon after his symptoms begun. He simply could not afford the care and treatment he needed, and so his condition deteriorated until PIH came and provided the free medications he needed, but a full year after his symptoms first begun.

Patient 5, 18-years-old, infected with HIV, had also tried going to the clinic earlier in the course of her symptoms, and when she was asked for money she returned home. For many people who cannot afford to pay for medical services, suffering and death are their only options once the local remedies fail. Patient 1, the 70-year-old woman, who had gone to St. Thérèse Hospital before Partners in Health arrived and was turned away for lack of funds, had a CD4 count of 264 cells/mm^3 and suffered with a painful zoster. She wanted to go to Cange but for five months was unable to go because she lacked the money for transportation. She remained in Hinche trying various home teas and body manipulations until her neighbors and family members raised the money that paid for her two-hour car ride to Cange. She returned to the St. Thérèse clinic months later while PIH was there and stated: *"I did not have to pay. That is why I am able to talk to you today."*

Patients who lack the financial means not only lack access to care once they are sick, but they also may also miss out on public health information about HIV disease prevention when that information is disseminated via the radio, a commodity which the majority of these patients lack.

c. Distance from the clinic as a barrier to care

While most, 74%, of the patients interviewed lived within a two hour walk from their nearest clinic, living at a distance greater than two hours from the nearest health center was significantly associated with late presentation to care ($p<0.005$). Increased distance from a clinic constitutes a barrier to obtaining timely medical care in rural Haiti. This is understandable especially when we consider that the population lacks the resources to pay for transportation to far clinics when they become symptomatic.

2. Intra-personal Factors

a. Patient gender

That 60% of those who presented late were male patients suggests that male sex is associated with later presentation for HIV care as hypothesized. Though this association was not significant in this study, other study findings by Samet et al showed male gender to be associated with later presentation for HIV care in the in the U.S. [10]. The higher proportion of male late presenters observed in this study could be explained by the fact that men tend to have less contact with the hospitals for general medical care. While women through pregnancy and prenatal visits might have more contact with the health care system, men do not have those opportunities. Female patients may be screened and diagnosed with HIV early in their disease process while still asymptomatic, through peri-natal care [10]. While many women, especially in rural Haiti, do not enjoy such prenatal care, those who make it to the hospital for pregnancy and gynecological-related issues may receive the benefit of HIV screening and be introduced to the health care system earlier than men.

Another possible explanation for the observation in this study may be related to the fact that the men interviewed more often believed that their symptoms was related to Voodoo and they sought *hougan* treatments which took time, thereby delaying their presentation to medical care.

b. Patient age

This study found that older age was significantly associated with late presentation for HIV care ($p<0.05$). The late presenters were on average eleven years older than the early presenters. The late presenters had a mean age of 43 years compared to a mean of 32 years for the early group. Samet et al also found older age to be significantly associated with lower CD4 count at presentation among patients in the U.S. [10]. Lack of basic education, lower socioeconomic status and a tendency to rely on the traditional medicines in that group may contribute to the circumstances that make this group present late for care. In general, the younger patients of this group more readily sought market pills for their symptoms while the older patients called on local healers. The younger patients through their activities, might be more familiar with the hospitals, and public health messages about HIV, which could result in lower threshold for seeking hospital care when they become symptomatic.

c. Patient belief system about the origin of their disease

For 97% of the patients interviewed, when they became symptomatic the chain of events to obtain help started with trying home remedies first. Teas and syrups made from various leaves, boiled roots, and other herbal remedies are tried and when these fail, some patients call on traditional healers to lay hands on them. Trying the home remedies first

seems to be common for all the patients regardless of educational or socioeconomic status. When these interventions provide no recourse and the patients realize that their symptoms continue to worsen, they either seek help at a local hospital, or if they believe that their symptoms are related to Voodoo (29% of the cases), go to a *hougan.*

Why do patients seek care from hougans?

When faced with a disease or phenomenon that they cannot explain, and for which they have not experienced effective therapy, in the setting of fear and poverty, some patients attribute their symptoms to Voodoo explanatory models, and therefore seek care from *hougans*. *Hougans* are familiar and accessible to the rural population; hospitals are not. While *hougan peristyles* or temples dot the landscape of rural Haiti, hospitals and clinics with appropriate resources are much harder to find. Patients who become symptomatic and do not know what is happening to them may fear harm from evildoers. They go to *hougans* who they believe can provide answers about motives behind any Voodoo spells and provide a cure for their symptoms.

Under these circumstances of poverty and lack of access to effective health care, patients go to *hougans* to find answers to events they consider mysterious or unexplainable. Even some people who don't readily believe in Voodoo, may also go to the *hougan* in order to rule out a magical wrongdoing. Patient 8, a 35-year-old man who presented for care early, was one such example. While he did not specifically believe that his symptoms were due to a magical disease, he nonetheless automatically sought the help of a *hougan* explaining *"I can't say what sickness I have exactly, I do not know of any issues that I have had with anyone, I just saw that I was bedridden."* For many in

rural Haiti going to the *hougan* is the first step in investigating an illness. Patient 20, a 49-year-old man elaborates:

> *"When someone is suffering they'll try everything in search of relief. The cramp of the disease had been ravaging my body I could not hold anything in my hands it was so painful. I started spending money outside of the hospital to find an answer."*

Patients also go to *hougans* if they feel targeted for harm by others. One common theme that drives the visits to the *hougan* is the fear that another person is trying to harm the patient. This harm is thought to be motivated by jealousy for economic means; therefore those individuals who went to school, learned a trade, had a steady job, and who felt like they were the object of envy, expressed being particularly targeted for the 'little that they have'. When patient 6, a 57-year-old economically stable bus driver and a late presenter, became symptomatic, he immediately thought that his disease was sent by jealous men, and sought *hougan* help. He explains:

> *"You know, we live in a country of evil doers and of the wicked, I don't quite believe that I suffer from a simple hospital sickness. I think someone is trying to do me wrong. They gave me a hit of magic powder or cast a spell on me."*

Patient 3, a 45-year-old seamstress who also presented late, spent a total of two years with a swollen leg and fever before finally going to the St. Thérèse Hospital just minutes from her house. She also believed that her disease was 'sent' to her and so sought help at the *hougans* first. She explains:

> *"Since they had always said that my sickness was sent by man, I did not go to the doctor. Everyone said that it was a magical disease, given by man, because of jealousy for the little that I have. I was doing well initially when I moved to this town with my sewing business. They say that someone meant to do me wrong because of my success here."*

Patient 20, a 49-year-old late presenter shares:

> *"The misery of sickness brought me to Hinche. When I arrived here no one believed that I would live, man had served me an illness. My wife was already sick in my hands, when they saw how I fought with her, and that they could not kill her, they sent the same disease to me. You know how wicked man can be. Man was always trying to break me, but they have not put me to bed yet."*

Patient 26, a 31 year-old man and late presenter, spent eleven months symptomatic before finally going to the hospital for his symptoms. When asked why he did not go to the hospital when his symptoms first begun, he replied: *"I thought it was another Haitian who wanted the little that I had who was doing this to me."*

Who goes to the hougan?

Although some women believed that their disease might be due to Voodoo, most who actually went to *hougans* for care were men with the exception of one woman. It is important to note that among the men who did not go to the *hougans*, Christian belief was the explained reason. Half of the people who went to the *hougans* were illiterate and the other half had reached high school. Therefore higher level of education did not seem to make going to the *hougan* less likely. These patients sought the *hougans*, followed their treatments whether they worked or not, for variable lengths of time, and subsequently presented to care late in their HIV disease process.

Time spent at the Hougan

Hougan visits usually mean an average of one-year delay to appropriate medical care during a time when the patients are symptomatic. Among the study group, patients who followed *hougan* treatments remained on these treatments for a range of 6 months to

seven years, before finally presenting for care at a hospital or clinic. Patients waited until the *hougan* treatments had failed and their symptoms had worsened before presenting to the clinic.

Money spent in local remedies and at the hougan

Since those who went to the *hougan* often felt like they were being targeted by jealous fellow Haitians and actually had some economic means, they were able to afford long treatment periods. The *hougan* treatments are not without cost and patients spend considerable amounts of time and money for them. Some patients spent months hospitalized at the *hougan*, and paid with their life savings for treatments that were ineffective. Patient 20 confesses: *"I amassed an insurmountable debt from the outside help. When one hougan is not effective, I get out and go to another one. Right now I just started going to a new one."* Patient 8 shares, *"I was sick and had spent plenty of money at the hougans. I was hospitalized at the hougans; for two months I was throwing money away."*

Patient 1 bought her *rabadou,* a type of homemade syrup, for $40 Haitian dollars (about 5 USD). Not an insignificant sum given that she has no income. Her daughter sent the money to her. Patient 6 bought some injections from a local doctor, *"I had to take more than forty total injections. They were twice a day at $22(Haitian dollars) per injection,"* the equivalent of 3 USD.

Negative physical side effects of some hougan treatments

Local herbal remedies like teas, syrups from roots, injections, physical manipulation, as well as Voodoo treatments not only have their own costs, but they also come with their own set of untoward side effects. *Hougans* and other traditional healers are not always effective. Patient 8 volunteered: *"I was sick and spent plenty of money at the hougans without finding a solution."* In fact some treatments can have very serious untoward effects. For example, the *hougan* practice of *vomi* that induces vomiting, can lead to dehydration and induce electrolyte imbalances in an already frail HIV patient.

Patient 1 who called for a body manipulator, became worse after the treatment given: *"When that person came, he beat and beat me and detached me, I spent three days passing blood by mouth."* Sometimes the local remedies can be outright disastrous. One practice of chasing away bad spirits by beating the patient on the head can do life-threatening damage (see figure 6 for example of untoward effect of *hougan* treatment).

Some people believe that intra-muscular injections with medications sold at the market cure many ailments. Others think the injections possess curative properties and they associate the pain from getting the shots with the potential cure of their disease. Patient 3 sought to cure her swollen leg and fever by getting injections from a local herbal doctor. Another HIV patient on ARV complained because his treatment regimen did not include injections. Because of this belief, local healers who provide injections for a variety of ailments have very busy practices. The needles used by these local doctors for the injections are often reused, and patients unknowingly put themselves at risk of getting HIV and other infections by receiving injections from the local healers. It remains to be seen how much of the HIV among the poor monogamous peasant couples can be

attributed to the injections they received with likely contaminated needles used by local healers

Why do patients continue to go to the hougan?

If *hougans* and local remedies aren't cheap and they can pose significant untoward effects, why then do patients spend their few hard earned dollars in those avenues instead of at a clinic? If it is believed that their disease is due to a Voodoo spell, those who can afford it will invest in ways that could rid them of the magical disease. Patient 18, a 36-year-old man elaborates:

> *"Haiti is a country full of magic, when you are faced with certain mysterious things, you will go to the sources where you feel you may find the answers."*

For many in Haiti who do not have access to basic education and public health education, the symptoms of HIV and AIDS can present as the mysterious symptoms that will precipitate their trip to the *hougan* for answers, despite associated negative physical side effects. The *hougan* doctor is embedded in Haiti's rural life and is part of the social structure of the community. They are familiar and accessible to the patient population and few other alternatives exist in the rural setting to help these patients deal with their diseases and symptoms.

When patients visit *hougan*, they are given tangible potions for their money, and they sometimes find symptomatic relief there. Patient 22, 33-year-old man and late presenter shared:

> *"I thought my disease was a Voodoo illness. The hougan helped me. I used to feel a weight in between my shoulder blades where the evil spirits sat, since the hougan treatments I no longer feel that."*

Patients will have faith in the *hougan* treatments if they receive relief from them. Patient 6 testifies:

> *"The last time I had a problem with going to the bathroom, it was a hougan who helped me go. He gave a lavement (an enema), and now I do this regularly. Another time he gave me a vomi (an emetic). I vomited and then I was able to go to the bathroom."*

It is important to note that while the patients seek help at the *hougan* and follow their treatments, patients do not exclude other effective therapies if they find them. Whether they believe in magic or not, all patients are looking for an effective remedy or cure for their symptoms. Once introduced to medical care at PIH, patient 6, a 57-year-old man, diligently took the antiretroviral medications prescribed to him while also continuing to see a *hougan*. *"I have people who give me potions and I continue to do what I can on the outside, going to hougans, and getting some more treatments."*

d. Patient perception of local hospitals and the effects on timing of presentation

Whatever the personal belief system about the origin of disease, going to the hospital is the last resort for most, for a variety of reasons ultimately related to their poverty. If magical or Voodoo beliefs do not factor into the person's belief system, they will try the herbal teas and market pills first, still delaying their visit to the doctors. Among this patient population, finding a traditional cure first seems to be the rule; and it is only when this fails that patients go to the hospital. The reasons why people do not seek the hospital first varies. Some patients simply were not familiar with the hospital, those who were familiar with the health care system held less than stellar opinions about the quality of care available from the local hospital.

Appropriate and reliable health care has not always been available in Hinche. While many of the patients had had some contact with the local health care system, 47% of the late presenters and 45% of the early presenters who had been to the hospital before were left unimpressed by their experiences. Because of the general lack of resources in the local hospitals, patients do not always receive effective treatments; and lack of relief from the medical services does not encourage patients to seek future care at the hospital.

Patient 5 went to a Port-au-Prince hospital when her symptoms first begun; she was prescribed medications which she took, but they did not help. As her condition worsened, she, like many other patients, returned home to Hinche. Patient 6 who was able to afford hospital consultations, sought medical care in Port-au-Prince, Pétion-Ville and in Hinche. He sought help in 2003 for generalized rash and skin eruptions. He did not get better with the treatments that were given to him but he was told he had a microbe in his blood. When he did not find a solution, and saw that his condition was worsening, he returned to his hometown, and called on a 'manipulator' or a local chiropractor and on a *hougan* to treat him.

Patient 26, a 31-year-old man, was also left without answers after trying the hospital the first time. When he became symptomatic with HIV, he avoided going to the local hospital. When asked why, he replied, *"I didn't believe in hospitals."* When asked "Why did you not believe in hospitals?" he answered: *"I had spent a lot of money there before, to the tune of $1,083 (Haitian dollars, about 155 USD) and their treatment did not do anything for me."* So the belief that hospital treatments can be costly and ineffective may keep some patients from seeking care there.

Negative ideas about the local hospital also play a role in delaying patient presentation to care. Some patients avoid going to the hospital even when they are symptomatic for fear that they might get worse if they go to the hospital. Patient 3 feared that her leg which was swollen would be amputated if she were to go to the hospital. She explains, *"Since my leg was swollen, I did not want to go to the hospital because if I went my leg would be cut off."* The belief that she would come out of the hospital minus one leg is not completely unfounded. Someone else from the community may have returned from the hospital with an amputation, perhaps as a result of advanced diabetes and gangrene or tissue damage from an accident or trauma.

Some patients seem to have a high threshold for suffering and many endure pain with their symptoms, going to the hospital only when their situation is unbearable. Patient 8 said: *"The disease did not put me to bed, perhaps if I had become bedridden I would have gone to the hospital earlier."*

When some patients finally decide to go to the doctor, many who hear about the Cange complex often prefer to go there. Patient 7, like other patients from Hinche, preferred to travel hours to Cange instead of going to the local St. Thérèse clinic in Hinche. Those who received prior medical care at the complex generally speak positively of the care they had received. Patient 4 explains, *"When I first got sick I went to Cange. They took care of me. They gave me medications."* People hear that the care is good, and patients recognizing the good care, seek it out when they become sick.

This study found that those who had been to Cange for other medical reasons were more likely to present early for their HIV care and this association was significant ($p<0.04$). All early presenters with the exception of one patient, had heard about Cange

and received care at the complex for a prior medical issue. All of the men who presented early, had been cared for at Cange in a prior occasion, they had heard about the free and good quality care there, and paid their way to the complex. Their good experiences there perhaps instilled a trust in the health care system contributing to their subsequent early presentation to the local hospital for HIV care.

Some patients explicitly stated that they would chose to go to Cange before going to St. Thérèse if they needed medical care. At PIH clinics like Cange, the patients are cared for without charge, and they report their experiences as generally positive compared to their local hospital experiences.

But not everyone makes it out to Cange. Some patients who could not afford the trip to Cange preferred to remain untreated rather than go to their local clinic. In this case, lack of trust in the local health care system allowed the patient to remain symptomatic without ever accessing the local clinic, only a walk away. Those who have money for transportation, mostly the men from this study, were able to go to Cange.

PART 5. PATIENT CONTACT WITH THE HOSPITAL FOR HIV CARE

The factors that motivate patients' entry into the hospital include failure of the local remedies and *hougan* treatments; symptom progression and worsening physical condition; encouragement to come to the hospital by family and friends; and hearing that PIH doctors were at the local clinic. Most patients present when their symptoms are debilitating, or when they have pain or a physical sign that does not respond to local remedies. Patient 7, a 22-year-old female, confesses that she came to the hospital because

"I did not get better with the teas and I was getting worse, when I arrived at the hospital the doctors wanted to hospitalize me."

Some patients were encouraged or forced to come into the hospital by family members and neighbors; and still others were actually picked up and brought to the clinic by PIH community health workers. One's own family and neighbors play a major role on a patient's decision to go to the hospital. Patient 7 states: *"I was so small that everyone knew that something was wrong, they forced me to go."* Patient 1 relates: *"Everyone was saying that I should be brought to Cange."*

Some patients are actually picked up by the community health workers and brought into the hospital. Patient 5, 18-years-old with HIV, had tried going to the St. Thérèse clinic before and was returned home for lack of money. She was later found by PIH community health workers who came in her neighborhood to look for the sick, and was brought to the clinic for care. This time to receive the medical care she needed at no cost to her.

For some patients, hearing about the coming of the Cange doctors to St. Thérèse Hospital served as an incentive to go there. Twenty-six percent of the patients came to the clinic when they heard that PIH services were available there. Patient 2 went to the hospital for the first time when he: *"Heard on the radio that the doctors from Cange would be coming to St. Thérèse."*

PART 6. THE DIAGNOSIS WITH HIV

Upon diagnosis, how do the patients react to being told that they have HIV? *"Sickness does not fall on trees it falls on people, so I accepted it"* patient 4, a 48-year-

old female. This is the tone with which most of the patients interviewed talked of their newly revealed HIV diagnosis. As a general rule there seems to be an acceptance of the diagnosis; others repeat: *"sickness does not fall on trees it falls on people, if they told me this, I must have it, I accepted it"* said patient 6, a 57-year-old man.

Some patients were unaware of their diagnosis even as they continued to take daily medications. It is estimated that only 5-8% of the HIV infected individuals worldwide are aware of their diagnosis [2] and many patients could not speculate as to how they might have contracted the disease.

When asked to state their biggest concern, not one of the patients responded that they were most concerned about their HIV status. Most were preoccupied with where their next meal would come from and how they would manage to survive. So their most pressing concerns have less to do with their HIV diagnosis and more to do with the poverty that they live in. These patients worry about food, shelter and their general life conditions; they are concerned with all the different issues that affect their survival.

VI. RECOMMENDATIONS FOR FUTURE RESEARCH AND POLICY

Because of its small sample size, this study was not powered to detect significant associations that could exist between male gender, lower education level and late presentation for HIV care. Larger studies could perhaps better define the roles of gender and education level in the timing of patient presentation to care.

Extreme poverty remains the common denominator for many of those who present to care with advanced HIV disease in Haiti. Those who presented late were older, poorer patients who lived far from medical clinics. The factors significantly associated

with late presentation for HIV care in this study population: patient age, socioeconomic status and distance from clinic along with other factors discussed can serve as guides for developing health recommendations that affect the poor and engage patients in care. To address the factors associated with late presentation of HIV, poverty, in all its forms, should be addressed. A multifaceted approach that includes, poverty alleviation strategies; expanded access to basic and health education; and improved access to free and effective medical care are needed to respond to the HIV/AIDS crisis.

Poverty alleviation strategies, such as improving farm production with irrigation, offering micro-credit schemes for rural residents to start their own small business, and encouraging economic opportunities in the rural areas to prevent rural to urban migration may also help reduce the economic conditions that force patients in situations of increased HIV risk.

Expanding access to basic education for the poor in Haiti, is important in the fight against HIV. Without basic literacy or numeracy skills, it is very difficult to move out of a situation of poverty which often sets patients up to become infected with HIV. Local health education campaigns that reach those in the rural settings to increase HIV awareness and knowledge about the disease risk factors, could reduce ignorance about symptoms: *"If I knew I had a doctor's disease I would have gone earlier,"* and influence patients to seek help earlier in the disease process. Health education would also make disease symptoms seem less mysterious; and would prompt patients to care perhaps before they visit a traditional healer. However, given the extreme poverty conditions, an education campaign alone will do little to curb the epidemic. Reaching out to the population with free and effective care is key.

Accessible, free, and effective medical services, bypasses the socio-economic barriers to medical care that exist in Haiti and many other resource poor-countries. Building more rural health clinics where patients can access basic HIV testing and care would decentralize the care, reduce the distance barrier to the healthcare center, and improve access to effective medical care. Appropriate and reliable medical care would increase patient faith in biomedical care provided at the hospital, and help dissipate the negative impressions that many patients hold about the local hospitals- -which, traditionally, have not been adapted to the needs of poor patients. As is known in Haiti, *pawòl palé* or word travels fast. Provide good and effective medical services and patients will come, and over time, trust in the services and effectiveness of hospitals would increase. This work has already begun in Haiti's central plateau through the medical services provided by PIH. Patients now flock to the St. Thérèse Hospital that had been all but abandoned a few months ago.

Traditional belief systems in disease causation may influence some to delay seeking medical care. While Voodoo belief and *hougans* are cultural components of the rural life in Haiti, they do not have to present a barrier to care. Informing patients about HIV and providing effective health care alternatives to the traditional healers may bring more patients to the hospitals earlier in the disease process. The goal in addressing late patient presentation in the context of Voodoo belief would be to collaborate with the *hougans* to inform them and the patients and about effective health care alternatives. This collaboration has already begun in the central plateau where some traditional healers and *hougans* have referred their very sick and untreatable patients to the St. Thérèse hospital. Many HIV-positive patients have been identified and introduced to care through this

partnership. The link between traditional healers and the allopathic healthcare system can be enhanced through the use of community health workers who can serve as a liaison to encourage and facilitate referrals of suspected patients with HIV infection from traditional healers to the hospital for HIV testing and medications. In addition, community health workers can be a valuable resource to help bring both education and voluntary counseling and testing to distant areas.

A multifaceted approach that includes accessible, free, and effective medical care, poverty alleviation, expansion of basic health education and collaboration with local healers is needed in the fight against AIDS in Haiti. These measures could lead to more effective HIV case detection, significantly reduce the number of patients who present late for HIV care, and reduce suffering and premature mortality from AIDS in Haiti and in other resource poor countries similarly affected by the AIDS epidemic.

Figures

Figure 1. Map of Haiti in the Caribbean

Figure 2. Map of Haiti's central plateau with the Partners In Health (PIH) five existing clinical sites and Hinche, newest PIH expansion site.

Figure 3. Site of present study: Pavillon Monseigneur DeCoste of the St. Thérèse Hospital in Hinche, central Haiti. Patient care provided by The Haitian Ministry of Public Health (MSPP) and Partners in Health "Zanmi Lasante" (ZL).

Figure 4. Distribution of symptoms for all study subjects at the time of presentation for HIV care at the Pavillon Monseigneur DeCoste in, St. Thérèse Hospital in Hinche Haiti.

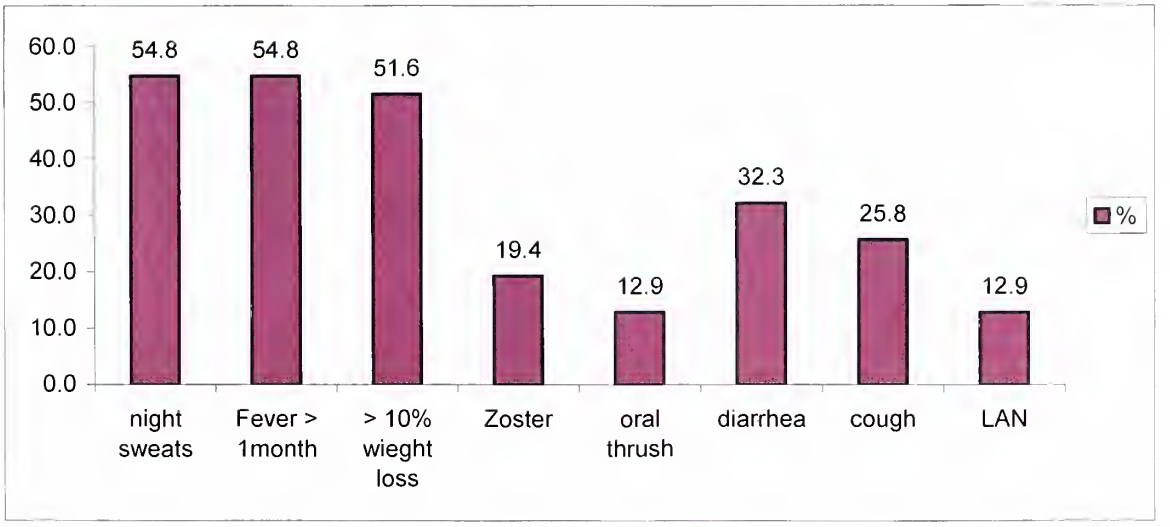
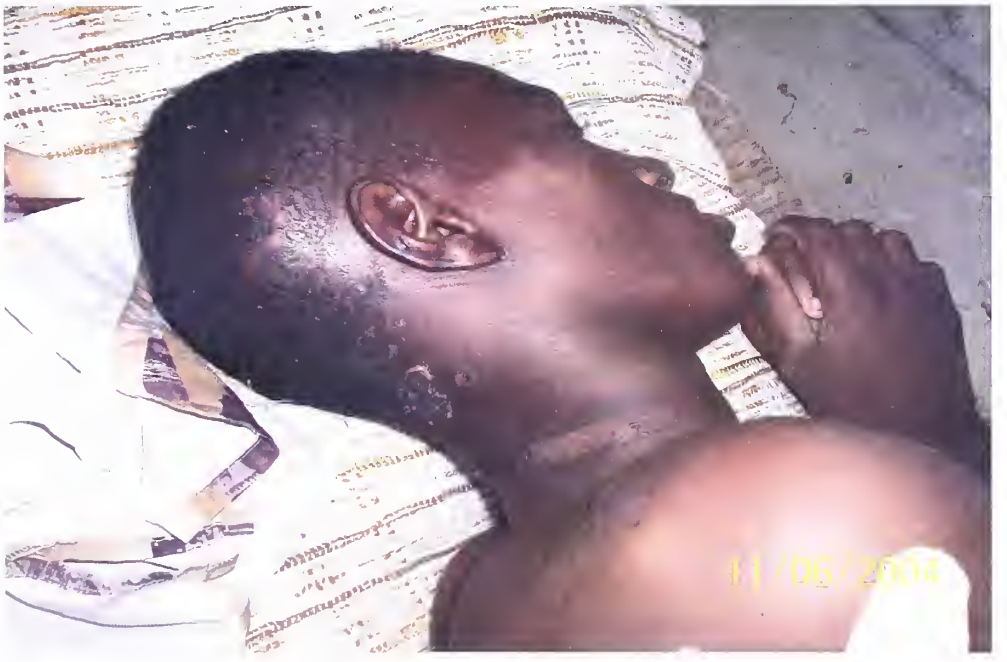


Figure 5. A typical peasant house in a rural commune of Hinche in Haiti's central plateau.

Figure 6. HIV patient in Haiti's central plateau presenting to care with cephalo-hematoma and neck burns following *hougan* treatment for symptoms.



REFERENCES

1. The Joint United Nations Programme on HIV/AIDS. www.UNAIDS.org Global summary of the HIV/AIDS epidemic December 2004. Accessed February 20, 2005.

2. Mukherjee J.S., Farmer P.E., Niyizonkiza D., McCorkle L, Vanderwarker C, Teixeira P, Kim JY. 2003. Tackling HIV in resource poor countries. *BMJ.* 327(7423):1104-6.

3. www.AVERT.org HIV/AIDS statistics. Accessed February 20, 2005.

4. The Joint United Nations Programme on HIV/AIDS. www.UNAIDS.org The UNAIDS 2004 Report on the Global AIDS Epidemic. Caribbean Fact sheet. Accessed February 20, 2005.

5. Farmer P., Castro A., 2004. Pearls of the Antilles? Public Health in Haiti and Cuba. In *Unhealthy Health Policy: A Critical Anthropological Examination.* Castro A., Singer M., editors. Altamira Press: CA.3-28.

6. World Health Organization: Emergency Scale up of Antiretroviral Therapy in Resource Limited Settings. 2003. Available at http://www.who.int/3by5/en Accessed february 20, 2005.

7. Inventaire des resources et potentialities d'Haiti.

8. Central Intelligence Agency. CIA World Fact book 2002. Langley, Virginia, UnitedStates,(www.cia.gov);(www.cia.gov/cia/publications/factbook/index.html).

9. Ivers L, personal communication.

10. Samet JH, Freedberg KA, Savetsky JB, Sullivan LM, Stein MD. 2001. Understanding delay to medical care for HIV infection: the long-term non presenter. *AIDS.* 15(1):77-85.

11. Samet JH, Retondo KA, Freedberg KA,Stein MD, Heeren T, Libman H. 1994. Factors associated with initiation of primary medical care for HIV-infected persons. *American Journal of Medicine.* 97(4):347-53.

12. Personal correspondence with Hinche PIH Program Director Dr. Pierre Paul.

13. Tashakkori A., Teddlie C., 2003. *Handbook of Mixed Methods in the Social and Behavioral Research.* Thousand Oaks CA: Sage Publication. 385-422.

14. Strauss A, Corbin J. 1998. *Basics of Qualitative Research, Techniques and Procedures for Developing Grounded Theory.* California: Sage Publications. London, UK pp 55-217.

15. SAS Institute Inc. *SAS/STAT Guide for personal computers version 8.2.* Cary, North Carolina:SAS Institute. 1987.

16. Farmer P. 1993. *AIDS and Accusation: Haiti and the Geography of Blame.* University of California Press.

17. Castro A., Farmer P., Infectious disease in Haiti. *Science & Society.* 4:20-23.

18. Smith Fawzi M, Lambert W, Singler J, Keonig S, Leandre F, Nevil P, Bertrand D, Claude M, Bertrand J, Salazar J, Louissaint M, Joanis L, Farmer P. Prevalence and risk factors of STDs in rural Haiti: implications for policy and programming in resource-poor settings. *International Journal of STD & AIDS.* 2003;14:848-53.

19. Munoz A, Carey V, Saah AJ, et al . 1988. Predictors of decline in CD4 lymphocytes in a cohort of homosexual men infected with Human Immunodeficiency Virus. *Journal of Acquired Immune Deficiency Syndrome.* 1:396-404

20. MC Smith Fawzi, ScD, P Jagannathan, BA, J Cabral, R Banares, J Salazar, BS, P Farmer, MD, PhD, H Behforouz, MD. Limitations in knowledge of HIV transmission among HIV-positive patient accessing case management services in a resource-poor setting. In press. Boston, MA and the Program in Infectious Disease and Social Change in the Department of Social Medicine, Harvard Medical School, Boston, MA.

21. Deschamps MM, Pape JW, Hafner A, Johnson WD Jr. Heterosexual transmission of HIV in Haiti. *Ann Intern Med* 1996;125(4):324-30.

22. Farmer P, Leandre F, Mukherjee JS, Claude M, Nevil P, Smith-Fawzi MC, Koening SP, Castro A, Becerra MC, Sachs J, Attaran A, Kim JY. Community-based approaches to HIV treatment in resource-poor settings. *Lancet.* 2001; 358 (9279):404-9.

23. Behets FM, Genece E, Narcisse M, Liautaud B, Cohen M, Dallabetta GA. Approaches to control sexually transmitted diseases in Haiti, 1992-95. Bull World Health Organ 1998; 76(2):189-94.

24. Farmer P., *Culture, poverty, and the dynamics of HIV transmission in rural Haiti.* In: Brummelhuis HT, Herdt G (eds.). Culture and Sexual Risk: Anthropological Perspectives on AIDS. Newark NJ: Gordon and Breach, 1995:3-28.

25. Farmer P., Sending sickness: Sorcery, politics, and changing concepts of AIDS in rural Haiti. *Medical Anthropology Quarterly*.1990; 4(1):6-27.

26. Hammersley M, Atkinson P. *Ethnography Principles In Practice*. New York: Routledge, 1989.

27. Ivers L, Jerome G, Joseph J, Fraser HS, Farmer P, Mukherjee J, Leandre F. Scale up of an HIV treatment program in rural Haiti. [Abstract] 15th International AIDS Society Meeting; July, 2004; Bangkok; July 2004.

28. Cates W, Dallabetta G. The staying power of sexually transmitted diseases. *Lancet*. 1999; 2000(354):SIV62.

29. Farmer P., The exotic and the mundane: Human immunodeficiency virus in Haiti. *Human Nature*. 1990; 1(4):415-446.

30. Cartoux, M et al. Acceptability of voluntary HIV testing by pregnant women in developing countries: an international survey. *AIDS* 1998.12:2489-2493.

31. Farmer P., Social inequalities and emerging infectious diseases. *Emerging Infections Diseases* 1996; 2(4):259-269.

32. Farmer P., *Ethnography, social analysis, and the prevention of sexually transmitted HIV infection.* In: Inhorn M, Brown P (eds.). The Anthropology of Infectious Disease. Amsterdam: Gordon and Breach, 1997:413-438.

33. Farmer P., Kim JY. Anthropology, accountability, and the prevention of AIDS. *Journal of Sex Research* 1991; 25(2):203-221.

APPENDIX

Appendix 1. Research tool, sample patient questionnaire

Interview Guide

English Transcript #
Date:

I. Biographic data

1. Sex:
2. Age:
3. Marital status:
4. How long have you been with this person?
5. If applicable when did the spouse die?
6. Was the spouse sick?
7. How did the spouse die?
8. How many children do you have?
9. Do the children go to school?
10. What is the name of the area where you live?
11. Patient's presenting symptoms at time of HIV diagnosis?
12. CD4 count:
13. Date of diagnosis?
14. Current treatment regiment?

II. Living conditions

1. Where were you born?
2. Is that where you grew up?
3. Who did you live with when you were a child?
4. How many people were in the house?
5. What did your parent/caretaker do for living when you were a child?
6. Can you describe the house you lived in?
7. When did you leave your parents place?
8. Where did you go?
9. Why did you leave?
10. What type of housing did you move into?

III. Education

1. Did you go to school?
2. What grade did you complete?
3. Why did you stop going to school?
4. Did you want to continue?
5. Did your siblings go to school?

IV. Economic Characteristics / Occupation

1. What do you do for a living?

2. What does your spouse do for a living?
3. How do you support yourself?
4. How much money do you make in a month?
5. Do you have any family members in Port-au-Prince?
6. Do they help you?
7. Do you have any family members in other countries?
8. Do they help you?
9. Have you ever been to Port-au-Prince to visit or to live?
10. What other cities or places have you visited or lived in?
11. Have you ever received food or money from the government or from other organizations?
12. Do you own the land that your house is on?
13. If you rent, how much do pay in rent?
14. Where do you find the money to pay the rent?
15. How many rooms does the house have?
16. What is the house made of?
17. How many people live in the house?
18. Do you have a bathroom?
19. Kitchen?
20. Radio?
21. Do you have a garden or a patch of land to grow food on?
22. Do you have any animals to raise?

V. Prior contact with Medical facilities /Access to Care

1. Had you ever been to the doctor before coming to Zanmi Lasante?
2. Where did you go?
3. Why did you go?
4. How did you like the care you received?
5. How did you first hear about the clinic St. Therese?
6. How far is it from your house?
7. How do you get there?
8. Do you spend your own money to get there?
9. Do you like the services you are receiving?

VI. HIV and patient's personal story

1. When did you first know you were sick?
2. What were your symptoms?
3. What did you think you had?
4. What did you do for your symptoms?
5. Did you try home remedies?
6. Did they help you?
7. Was anyone aware that you were not feeling well?
8. When did you go to the hospital?
9. How much time elapsed between onset of symptoms and presentation to hospital?
10. When your symptoms first begun why did you not go to hospital?

11. What would have made you go to the hospital earlier?
12. Why did you go to the hospital at the time that you did?
13. Did anyone go with you to the hospital?
14. Did you undergo any tests?
15. What did the tests show?
16. What disease were you told that you had?
17. How did you receive the news that you had HIV?
18. How are you doing with the illness?
19. What do you know about HIV?
20. How is it transmitted?
21. What are some of the symptoms that someone with HIV can present with?
22. How can one protect oneself from HIV?
23. What are you doing to protect yourself?
24. Identify specific factors in your life which you think have helped to bring you where you are today.
25. How do you think you contracted HIV?
26. Do you know if anyone that you have been with has fallen sick?
27. What did your previous partners do for a living?
28. Had they traveled to Port-au-Prince?
29. What did they do for a living?
30. Does anyone else know that you have HIV?
31. If yes how do they treat you?
32. Do you know anyone living with HIV?
33. Would you like to know other people living with HIV?
34. Do you have any questions?

Thank you!

HARVEY CUSHING/JOHN HAY WHITNEY MEDICAL LIBRARY

MANUSCRIPT THESES

Unpublished theses submitted for the Master's and Doctor's degrees and deposited in the Medical Library are to be used only with due regard to the rights of the authors. Bibliographical references may be noted, but passages must not be copied without permission of the authors, and without proper credit being given in subsequent written or published work.

This thesis by
has been used by the following person, whose signatures attest their acceptance of the above restrictions.

NAME AND ADDRESS **DATE**